



Open Data and the Importance of Confidentiality, Control and Public Benefits

Dr Mhairi Aitken

Usher Institute of Population
Health Sciences and
Informatics

Concordat on Open Research Data

The Concordat on Open Research Data has been developed by a UK multi-stakeholder group. This concordat will help to ensure that the research data gathered and generated by members of the UK research community is made openly available for use by others wherever possible in a manner consistent with relevant legal, ethical, disciplinary and regulatory frameworks and norms, and with due regard to the costs involved.



Published 28th July 2016

“The benefits from opening up research data for scrutiny and reuse are potentially very significant; including economic growth. Increased resource efficiency, **securing public support for research funding and increasing public trust in research.**”

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What are the conditions for public support?

There is widespread public support for data sharing and data linkage for health research. However this support depends on a number of assurances:



If people trust the organisations handling their data they are more likely to be supportive.



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Aitken, M., et al 2016. 'Public responses to the sharing and linkage of health data for research purposes'. *BMC medical ethics*, 17(1)

Key conditions for public acceptability of research uses of data

- Confidentiality
- Control
- Public Benefits

Confidentiality

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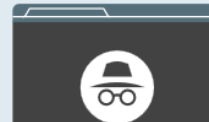
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Trust and Trustworthiness

- Underpinning each of these conditions is trust. This is fundamental to maintaining a social license for research practices;
- But instead of focussing on how to increase public trust we should instead focus on ensuring the *trustworthiness* of research.

Closing thoughts

- ◉ With ever-increasing amounts of data being collected combined with advances in computer power and data analytics the way that research is being conducted is changing. Such developments are opening up new possibilities for research whilst simultaneously raising new ethical dilemmas.
- ◉ Maintaining a social license for this research necessitates continual reflection on the conditions for public support; thinking about data not just in terms of how it relates to research but also how it relates to people's lives.

Recent Relevant Publications:

Aitken, M., Cunningham-Burley, S., & Pagliari, C. (2016). Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme. *Science & Public Policy*, 43(5), 713.

Aitken, M., Jorre, J. D. S., Pagliari, C., Jepson, R., & Cunningham-Burley, S. (2016). Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. *BMC medical ethics*, 17(1), 73.

Thank you,

Dr Mhairi Aitken

mhairi.aitken@ed.ac.uk